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Perceived health status in multiple sclerosis patients

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Summary

Most people live with an ‘illusion of invulnerability’. After diagnosis of a chronic disease like MS, this illusion is broken, and this loss of perspective may be devastating, particularly in early or middle adulthood. Disease onset of MS before the age of 10 or after the age of 50 is considered rare. A number of large epidemiological studies, but not all, on the natural history of MS have found that late age of onset, male gender and a short interval between onset and first relapse are associated with a poor prognosis. The progression of MS has been related to worsened functional disability as expressed in MS patients by Kurtzke’s EDSS scale. As the measures of perceived health status include physical health dimensions, functional disability and health status outcomes reported by MS patients may be linked very closely.

Chapter 1 of this thesis elaborates on the background of MS, with its clinical criteria, treatment and prognosis. This is followed by a general model of disability and by health status as applied in MS. Terms like *disease*, *impairment*, *disability*, *handicap* and *quality of life* established in the International Classification of Impairments, Disabilities and Handicaps (ICIDH) might be considered in the context of MS outcomes. At the end of this chapter, the aims of the study and research questions are formulated, focusing on a review of the literature on disease duration, functional disability, psychological well-being and perceived health status in MS (Chapter 2); self-rated health and its association to employment status in MS (Chapter 3); social support provided by family, friends and significant others and its positive associations with perceived physical and mental health status (Chapter 4); the associations of mastery, functional disability and perceived health status in MS (Chapter 5); and finally, the relationships between depression, anxiety and perceived health status in the whole sample as well as separately in the younger and older groups of MS patients (Chapter 6).

Chapter 2 reviews recent studies concerning perceived health status in MS patients as measured by the Short Form-36 Health Survey (SF-36). The study focuses on the use of the physical and mental health dimensions of the SF-36 that are linked to clinical data (disease duration and functional disability) and psychological well-being (depression). A computer-aided search in Medline and PsycINFO resulted in 504 articles in English published from 1996 to August 2006. Just 8 articles consisted of empirical MS studies in which perceived health status was evaluated using the SF-36. MS patients with low functional disability, shorter disease duration and minor depression scored significantly better than

patients with high functional disability, long disease duration and major depression in the SF-36 health summary scales.

Chapter 3 focuses on the association between the self-rated health of MS patients and employment status. Self-rated health was chosen as the first item of the SF-36 for a short subjective screening of health status. In addition to self-rated health, other important variables, including functional disability, disease duration, depression and anxiety, were examined as independent variables, while employment status was treated as a dependent variable. Results showed that MS patients who reported good self-rated health were more likely to be employed, less disabled and less anxious. Age, gender, disease duration and depression showed no statistically significant association with employment or non-employment in MS patients. It should be mentioned that only about half of the surveyed MS patients were employed full-time or part-time, although 68% of all patients belonged to the relapsing-remitting clinical course. This means that the possibilities of MS patients of being employed are really limited.

Perceived social support has shown its usefulness in the chronically ill as a psychosocial factor and coping strategy. People who look to others to support them report feeling strengthened and encouraged. Having someone who openly and willingly talks about MS and its challenges provides a patient with a positive coping style. The first aim of the study, described in Chapter 4, was to assess the association between social support provided by family, friends and significant others and perceived physical and mental health status in MS patients. The second aim focused on evaluating the social support provided by family, friends and significant others in association with the separate dimensions of perceived physical and mental health status. Social support from significant others was positively associated with the general health dimension of perceived physical health status, while social support from family and friends was positively associated with all four dimensions of perceived mental health status. The results show the importance of supporting social ties and relationships between MS patients and others.

Along with social support, mastery, as in having a sense of control, was identified as an important variable in a patient's psychological well-being. Chapter 5 deals with the associations between mastery, functional disability and perceived health status in MS patients. With regard to age and the use of disease-modifying drugs, differences were expected in mastery, functional disability and perceived health status between younger and older age groups of MS patients (<45 and ≥45 years of age). Patients with low functional disability reported better physical health status in both age groups and better mental health status in the younger age group. Mastery was positively associated with perceived health status in the older age group. The findings confirmed that mastery might be

helpful for older MS patients, while functional disability appeared to be the most important variable for younger age group.

Depression and anxiety were found to be significant variables associated with perceived health status, as described in Chapter 6. Comparable to Chapter 5, the study sample consisted of 223 MS patients who were divided into two age groups (<45 and ≥45 years of age). The role of depression was present with regard to perceived health status, mainly to perceived physical health status in the older group and to perceived mental health status in the younger one. The role of anxiety was more important in younger MS patients than among older patients with regard to their perceived health status.

Finally, in Chapter 7 the main findings of the studies described in this thesis are discussed and placed within a broader context. This chapter also reflects the importance of the model used as the framework for this thesis. The chapter ends with a discussion on the clinical implications of the work.

Several recommendations are made about directions for future research and practice: to continue this research in a longitudinal study in order to compare both cross-sectional data and longitudinal data; to extend the theoretical framework by adding new variables; to support better perceived health status in MS patients through rehabilitation and neuro-rehabilitation approaches; to follow up with psychosocial interventions, including cognitive-behavioural therapy, social support, group therapy etc.; to provide a multidisciplinary approach in symptom treatment that would be directed toward patients with MS.

Unexpected worsened disability may affect patients with MS fearing prognostic uncertainty, and they should thus become well informed about their illness. Collaboration is essential in the plan of care between patient, family and health care providers. Treating physicians should continually assess the need for psychological support for patients and their families, since depression is common and the rate of suicide is relatively high in this population of patients. Therefore, a multidisciplinary approach is needed for several of the complications of MS that may involve specialists in physical medicine and rehabilitation. Recent progress in treatment showed that advanced magnetic resonance imaging (MRI) and spectroscopy may allow clinicians to follow the pathological progression of the disease and to monitor the response to treatment. In parallel with the development of new diagnostics methods and clinical treatments, researchers have recently begun to recognize the association between disease progress and the psychosocial factors of MS.

